Understanding the Impact and Utilization of Home and Community-Based Services (HCBS) among Medicare-Medicaid Enrollees of Color

December 2022

PREPARED FOR:

ICH is a nonprofit consulting organization that provides participatory evaluation, applied research, assessment, planning, training, and technical assistance. ICH helps healthcare institutions, government agencies, and community-based organizations improve their services and maximize program impact.

Contents

INSTITUTE FOR COMMUNITY HEALTH

Understanding the Impact and Utilization of Home and
Community-Based Services among Medicare-Medicaid
Enrollees from Communities of Color

1

Introduction

With generous support from the Laura and John Arnold Foundation, the Center for Consumer Engagement in Health Innovation at Community Catalyst examined Home and Community Based Services (HCBS) utilization among dually-eligible people of color age 50 and older. The project sought to understand the impact of HCBS on dual-eligible beneficiaries of color who are age 50 and older, with a particular focus on potential disparities in access to care. This research will lead to policy recommendations that enable policymakers to develop better-informed policies to address racial and ethnic disparities in a set of services that are widely recognized as instrumental in helping people age in place in their homes and communities.

The project had three key components:

1. The first component was a literature review and quantitative data analysis. In the report from this first component of the study, titled "Racial and Ethnic Disparities in Access to Home and Community-Based Services (HCBS) Among Medicare and Medicaid Dual Eligible Populations: An Environmental Scan of the Literature,'' it was found that across all population groups, patients who need care support for activities of daily living prefer to remain at home or within the community whenever feasible. Currently, over one-third of individuals who are dually eligible for Medicare and Medicaid rely on home and community-based services (HCBS) for care – enabling them to stay in their communities and avoid moving to an institutional care setting. The report summarizes the literature showing that a disproportionate number of individuals who are dually eligible are comprised of racial and ethnic minority populations. Significant racial and ethnic disparities in access to HCBS exist, which additionally affect the health and well-being outcomes of these populations. These disparities need further inquiry to determine causation, particularly in terms of dually eligible people of color. There is also a pronounced need for qualitative research that directly engages the perspective of dually eligible people themselves.

2. In the second component of the study, interviews were conducted with content experts and other stakeholders in HCBS. In these interviews, stakeholders identified two main themes related to access to HCBS, which were: (1) challenges due to knowledge and navigation of the system, and (2) challenges due to HCBS care and service infrastructure. Quality barriers and challenges to HCBS also fell into two themes: (1) challenges due to a lack of equity focused data, and person-centered data in general, and (2) a lack of culturally appropriate and linguistically accessible care.

3. This report is the final and third component of the study, designed to better understand both the utilization and impact of HCBS among dually-enrolled Medicare-Medicaid enrollees from communities of color. We convened focus group sessions with enrollees across four regions of the U.S. (Northeast, Midwest, South and West) in order to:

INSTITUTE FOR COMMUNITY HEALTH

Understanding the Impact and Utilization of Home and Community-Based Services among Medicare-Medicaid Enrollees from Communities of Color

2

- Capture a range of views regarding why individuals have or have not used HCBS and the barriers and opportunities they encountered when attempting to access these services;

- Solicit information from people living in different areas of the country with varying service delivery and financing structures to better understand the widest range of views on access and experience across the country, and;

- Capture the diversity of racial and ethnic identity, HCBS needs, and disability status of people enrolled in both Medicare and Medicaid.

Methodology

A total of eight (8) focus group sessions were conducted virtually with people from five states enrolled in both Medicare and Medicaid. We conducted two groups in Arizona, two groups in Pennsylvania, and one group each in Alabama, Tennessee, and Michigan. Participants were recruited by Community Catalyst through partnerships with beneficiary advocacy organizations within each state[1]. Discussions focused around the following topics:

- Commonly used HCBS services
- Reasons and basis of the choice involved in selecting a service provider
- Experiences with past and current HCBS
- Racial and ethnic disparities in HCBS access and use
- Suggestions for ways to improve HCBS and reduce racial and ethnic disparities in access to and use of HCBS

Recruitment criteria

The recruitment criteria for focus group participants were:
- At least 50 years of age
- Actively enrolled in both Medicare and Medicaid (dually enrolled)
    - Either past or current experience with HCBS services
- Not self-identifying as White or Caucasian

Description of participants

Table 1 describes the demographic information that we have about participants and how that information is distributed by state. Most of our participants were between 50 and 59 years of age (57%) or between 60 and 69 years old (32%). Participants were asked to self-identify their race or ethnicity (and they were invited to pick as many categories as applied). For the 71% of participants who did identify by their race or ethnicity, the large majority identified as Black or African American (90%). Three participants identified as Native American (8%) and one as Latinx

---

INSTITUTE FOR COMMUNITY HEALTH

Understanding the Impact and Utilization of Home and Community-Based Services among Medicare-Medicaid Enrollees from Communities of Color

3

or Hispanic (3%). Participants were asked who they lived with, and what their current living situation was. More than half said they lived with family (54%). Just over one third said they live alone (34%) and another 12% said they lived with a partner. Finally, participants were asked what health care source they routinely sought when they needed care. Most indicated that they use a primary care physician (63%). Another 20% use a clinic or service as their routine health care source. Only three participants depend on the emergency room (ER) as a usual source of care or have no source of health care (6%). We did not notice meaningful differences between states in these data.

Table 1. Participant characteristics

	Alabama N = 7	Arizona N = 18	Michigan N = 7	Pennsylvania N = 13	Tennessee N = 7	Total N = 52
Age Range						
50-59	2	11	0	9	3	**25**
60-69	2	1	0	4	2	**14**
70+	3	4	2	0	1	**5**
Missing Data	0	2	5	0	1	**8**
Ethnic/Racial Identities						
Black/African American	5	12	0	13	6	**36**
Native American	0	3	0	0	0	**3**
Latinx/Hispanic	0	1	0	0	0	**1**
Missing Data	2	2	7	0	1	**12**
Living Situation						
Alone	3	0	6	5	3	**17**
With family	2	12	1	8	4	**27**
With partner	0	6	0	0	0	**6**
Missing Data	2	0	0	0	0	**2**
Usual source of care						
Primary care physician	0	13	4	9	7	**33**
Clinic or service	3	2	2	1	0	**8**
ER or none	2	0	0	1	0	**3**
Pharmacist	0	1	0	0	0	**1**
Missing Data	2	2	1	2	0	**7**

INSTITUTE FOR COMMUNITY HEALTH

Understanding the Impact and Utilization of Home and Community-Based Services among Medicare-Medicaid Enrollees from Communities of Color   4

How HCBS fits into overall support networks, including family care

Positives and negatives of family care and paid care

One of the research priorities for this project was to understand participants' preferences about receiving care from paid care providers versus from family members. Participants in our focus groups often held strong opinions about whether they prefer to receive care from paid caregivers versus family members. However, roughly equal numbers of participants preferred paid caregiver and family caregivers. Participants shared both positives and negatives for receiving care from both family and paid caregivers.

Family is more reliable: Care recipients described differences in reliability between paid and family caregivers, however, this difference wasn't in a consistent direction. Some people felt that family was more reliable than paid caregivers:

> *"If you get outsiders [paid caregivers], they may be good for a moment but some of them get lackadaisical. They be on their phones. They be on their phones. Yeah. They do nothing."*

Paid care is more reliable: On the other hand, some described difficulties in managing family caregivers in the same way:

> *"I would rather keep it professional, myself. I would keep it professional because sometimes family, they get lackadaisical. I would really [rather] continue my services professional because anything goes wrong, then we have paperwork."*

Alleviating need for family care: Some advantages of using paid caregivers that participants described included relieving their worries about needing a great deal of assistance from their family members. When talking about the demands of caregiving on family members, participants talked about disruption of family's ability to do paid work or schooling, being a strain on the family member's energy levels, or taking time

> **TAKEAWAYS: FAMILY CAREGIVERS VS PAID CAREGIVERS**
>
> - **Participants agreed about what they need from caregivers:**
>   - **Trust**
>   - **Caring relationships**
>   - **Dependability**
>
> - **Different participants saw advantages and disadvantages with using paid caregivers versus family**
>
> - **People felt strongly about whether they preferred family or paid caregivers – roughly equal numbers preferred one or the other**
>
> - **Managing caregivers – regardless of whether they are paid or family – takes work**

Understanding the Impact and Utilization of Home and Community-Based Services among Medicare-Medicaid Enrollees from Communities of Color

5

INSTITUTE FOR COMMUNITY HEALTH

away from caring for other family members including children.

> *"Plus, [family members] have to care for themselves and they have to take care of their mental health. They should not have to stop living so that we can have basic things. People say, 'Oh, that's what family does.' No, that's not what family does. Family loves you and that's a part of showing love when they do that but they have a life, if they stop their life to wait on us to just to die, they would never live because none of us know the day, time or whatever."*

Family care entails dependence and obligation: Participants also talked about the strain that dependence and obligation puts on their relationships.

> *"My family has caught caregivers just pulling into my driveway clocking in, saying they're here and then backing out and clocking out. They should be made to clock in and clock out in a home where they're supposed to be working at that time."*

> *"Sometimes you get a lot of help from someone, even from a family member. When you get too much help, you feel uncomfortable. Some people they feel that you depend on them too much. Maybe you become a burden to these people."*

> *"I always feel that despite the fact a family member knows you … it feels like they will require something in return. They just cannot do something for you, and maybe you will not pay them back or do a favor instead. That's how I feel. Maybe they need a favor in return after providing services for you, they'll need something back in return. … sometimes you may not have to pay for them. But it just feels like you owe them something, yeah."*

Paid caregivers provide more confidentiality: In one group, participants discussed a preference for paid caregivers because of the perception that these paid caregivers were more able to protect the participants' confidentiality around their medical conditions compared to family members.

> *"[T]here are also those medical condition or maybe the help that it will be better when you getting them from a [paid caregiver]. These are maybe I can talk about the confidentiality, the information that you don't want maybe to expose. I think it will be better for you to get it from a [paid caregiver] because it won't be exposed as in most probably, they won't tell anyone that knows you."*

Family is more trustworthy: Many participants had a strong preference for family caregivers. Family members were understood as being more trustworthy, whereas there was a great deal of

INSTITUTE FOR COMMUNITY HEALTH

Understanding the Impact and Utilization of Home and Community-Based Services among Medicare-Medicaid Enrollees from Communities of Color

6

concern about the risk of trusting a paid caregiver to be in one's house, having access to financial information.

"But sometimes I have to look at it now, you know, my daughter's been... been a caregiver for me for probably three or four years. I think it's putting a toll on her. I'm trying to think how to take some of the load off of her because she has two kids of her own and they're not... They're teenagers and she's the only one. She is really taking care of her own household and the two teenagers. I feel that that's taken a lot from her trying to help me and trying to be in two different situations."

"I had to have people come in and I really didn't trust anybody because I use a debit card and I have on a food stamp card and I didn't want my food stamp or debit card in somebody else's hand and they'd be abused."

Family is more loving: Participants also talked about the relationship and love they shared with family members. Family members genuinely care about participants; they're not just doing the work to receive a paycheck. Family members can better understand the participants' needs and preferences, and therefore potentially require less active management. Others said that family members also provided company and social contact in ways that paid caregivers could not.

"I love it when I get care from a family member, because they are always with me, and they know how to cheer me up when I'm down at times. I need someone to talk to."

Combining paid and family care

It also became clear that the quantitative data around whether people were using paid or family care masked a more complex reality. Participants seldom *only* used paid caregivers – instead, those receiving paid care usually creatively combined paid care with family assistance in several different ways. Thus we see that paid care is just one strategy in the toolkits of our participants.

Participants described combining family and paid care in several different ways. First, it emerged clearly that managing caregivers – both paid caregivers and family caregivers – requires active engagement. Family members may take on this coordinating role, which includes scheduling for needed coverage, organizing and assigning tasks, and monitoring and quality checking.

INSTITUTE FOR COMMUNITY HEALTH

Understanding the Impact and Utilization of Home and Community-Based Services among Medicare-Medicaid Enrollees from Communities of Color

7

"[My mother] was there to guide them to make sure because she knew what I liked, what I didn't like, what was supposed to be done this way and that way. My mom always made sure, 'You know you got to do it like this.'"

Several participants also described how family members were key in covering gaps in care provided by paid caregivers.

In other cases, the paid care served to relieve the pressures associated with caregiving and provide respite for family caregivers.

"I also utilize my family for services in the event that one of my regular caregivers cannot make it for one reason or another. For the most part, it's wonderful. They have no problem in coming in and filling in where I need them to fill in and just doing all of my total care as usual. It's wonderful to have a supportive family around to help out when you need them to come and help out."

"In terms of my family, my granddaughter, before I joined [provider], if I had a doctor's appointment, she would have to take off from work. I tried to make all of the appointments at a time where she wouldn't miss too much work. Well, after [I joined provider] my granddaughter has never had to take time from work. She never had to go to the pharmacy to pick my meds. They come to my door like clockwork every month. She loves it."

In some states, family can be compensated for the caregiving work they do through the state's Medicaid waiver program. In other cases, care recipients may have decided to compensate their family members themselves. However, participants described both pros and cons to combining these two types of relationships – i.e., having a family member also be a paid caregiver. Challenges here included difficulties with managing the labor of family members and holding them accountable for getting the work done.

"Sometimes it's hard for my family to look at the situation like employee-employer type situation."

We described above how some participants were concerned about their relationships with family caregivers due to the strain put on those relationships by their dependence on this care.

INSTITUTE FOR
COMMUNITY
HEALTH

Understanding the Impact and Utilization of Home and
Community-Based Services among Medicare-Medicaid
Enrollees from Communities of Color

8

Participants described working to ensure that the relationships with their family caregivers are more than just transactional but include elements of reciprocity. For example, a number of participants described ways in which they gave care to their caregivers. Most commonly, participants described the care they gave to family members, including concern about emotional and physical demands of caregiving and strategizing to reduce the pressure on their family members who provide care to them.

"But if I go to get groceries, that means that, a portion of the groceries, you give this person who's with you [paid caregiver] because it feels evil not to do that because we've all been taught to share. So, on that day... She knows, when my food thing comes in, she's all smiles and everything. So, these are needy people too. Everybody is in need. Nobody wants to admit it, but everyone is in need of some sort."

In a couple of cases, too, participants described ways in which they provide care for their paid caregivers:

> *"My family is very persistent about education. So, when they come in, I say, 'Are you going to school? Are you doing this?' So forth and so on. 'Okay. That's good. You need to keep going. Don't give up.' So, I can be an encourager to them as well as, hopefully, they can be encouraging to me."*

> *"A lot of people are just doing [paid caregiving work] because they feel, yes, they need that paycheck, but it's not really enough for them to take care of their families on.... you know they're not getting the money to really live off of. Basically, it's supplemental income, and it's not even a good supplement income. ... So, if you have things in the house, for instance, like she said, if they have children, that they're going to need food. So, you might have a can of juice or maybe some raisins or something that you can give them to help them out."*

Therefore, it is clear that participants are understanding their relationships with caregivers as needing to be genuine relationships characterized by elements of reciprocity, not merely as transactions.

Experiences starting HCBS use

Another goal of the project was to identify the experience of participants with HCBS services, including questions about a) where they first received information about the services, b) how

Understanding the Impact and Utilization of Home and Community-Based Services among Medicare-Medicaid Enrollees from Communities of Color

9

INSTITUTE FOR COMMUNITY HEALTH

much choice they felt they had while selecting their care provider and c) what they used as the criteria for selecting a particular provider.

Where information came from

Participants provided varied responses when it came to where they received information about finding HCBS. Most often, participants mentioned their social circles and referrals from care coordinators as important sources of information on where to get HCBS. Notably, no participant described a conversation with a health care provider as a source of information about HCBS.

Family set up services or assisted: In many cases, the details we heard from our participants about the way their services were set up was vague. Many people said they received help with setting up services from family members – this may indicate that our participants were not always the primary decision-makers in setting up their care, and therefore may not be the best source of information about the decision-making process.

Social networks: In a pattern that is consistent with the need to have relationship-based care, many participants described receiving information about HCBS services from friends, acquaintances, family members, and colleagues. This included both the 'where' and the 'how' to get services.

> *"I had a colleague, who is also a friend of mine, call until this May to someone who knew where I could obtain a service provider and the formalities."*

> *"I just heard about it when we would go to church and one of the ladies went to church with me and she'd be talking about it all the time. So, my ears would pique up."*

TAKEAWAYS: SELECTING HCBS SERVICES

- **Focus group participants got most of their information about HCBS from family or social networks. Referrals from services organizations or health plans were also a source of information.**

- **Participants described selecting paid providers based on personal recommendations, being eligible for the service, cost, finding a provider who was willing and able to provide appropriate services, and quality.**

- **Participants defined high-quality HCBS providers as those who were reliable, willing to build relationships, and trustworthy.**

It was clear that some participants heard about formal HCBS services through their social circles, while others had heard about particular individuals who could be hired informally through these means.

INSTITUTE FOR COMMUNITY HEALTH

Understanding the Impact and Utilization of Home and Community-Based Services among Medicare-Medicaid Enrollees from Communities of Color   10

"I was also referred by a friend. He is my close friend, and he knew somebody, like a caregiver. After he saw my situation, he referred me to him, and yeah. That's how I came to know the caregiver."

Referrals: Some participants reported receiving information and referrals for different HCBS care providers from care coordinators. Participants also described being referred to HCBS services through advocacy and support organizations for individuals with disabilities.

Some participants mentioned that they received information on HCBS services when they had enrolled in Medicare and Medicaid.

"I first became familiar with home and community-based services... Oh, well, kind of telling my age. It was in the early 80s and it was a different program by name back then. I became aware of it through Easter Seals."

"Well, it all started for me when Medicare and Medicaid kicked in and I had my insurance and they sent me out stuff, information on what services I can get."

Other sources of information: One group of participants from Tennessee mentioned that they received information from a senior citizens book which had all the necessary resources to support older adults. They further continued to explain that the book contains a list of services with working hours and contact numbers. One participant had knowledge of care resources through their own prior work as a care advocate for others.

Basis for selecting a service provider

Appropriateness and willingness: Participants shared that seeking service providers who were an appropriate fit for their needs was a critical consideration when setting up care. Participants described challenges in finding appropriate and willing staff who could provide the services that are essential to their daily lives, which may include personal tasks.

"It was hard to find someone who was comfortable with going to the shop, and purchasing those things, and comfortable to change [a stoma bag]. Maybe she's not in a position to change and all that. I handled this. This is too much, you know. She had to go from one place to another looking for a person who was willing to do that."

INSTITUTE FOR COMMUNITY HEALTH

Understanding the Impact and Utilization of Home and Community-Based Services among Medicare-Medicaid Enrollees from Communities of Color | 11

Personal recommendations: When seeking appropriate caregivers, trust was also a very important selection criteria. When participants didn't have enough information to make a decision, they relied on recommendations from friends and family regarding service providers.

> *"At first I was not so much informed. I did not have enough information about them, so I just choose as my friend had explained to me. He showed me which he thought would suit me better, so that is what I choose."*

> *"My family asked me to settle with [one] choice, because they had also heard about the plan from a friend."*

> *"I did have the best advice from [my] brother. He had experience in that field, so I preferred to make his choice, because he knew what he was doing."*

Navigating eligibility: Eligibility requirements for HCBS services sometimes limited participants' choice in selecting services. Participants perceived that different programs had different eligibility requirements, and they described challenges in navigating these requirements.

> *"With the program that I'm in, the Act 150 program, they tell me that I'm just eligible for the caretaker service. They tell me I'm not eligible for all of those other services unfortunately. I don't know. Everything's been so confusing. You hear one thing from the service coordinator. Something else from the agency. Something else from a friend of yours who will say, 'You should get this. You should get that.' Then when I call, they're like, 'No, you can't get this. You can't get that.' I don't know."*

Cost: For some participants, cost and affordability was also a factor to consider while selecting a provider.

> *"For me, I took it on cost ... Someone who I can afford to pay."*

Trial and error: Finally, a few of participants described trying different services at different agencies until they found one that worked best for them.

> *"I've gone through several care aides, and no. Until I got the last one and then the agency shut down. But I'm saying you got to kiss a lot of frogs before you kiss the prince. That's the same way it is with home care services."*

Perceptions about quality of services

When participants were asked for their perceptions of the quality of services and any gaps in this quality, they described their thoughts on the ideal qualities and characteristics of a care

INSTITUTE FOR COMMUNITY HEALTH

Understanding the Impact and Utilization of Home and Community-Based Services among Medicare-Medicaid Enrollees from Communities of Color   12

provider and their experiences with the quality of care of providers, both professional and paid family members.

Participants described various characteristics of a care provider associated with good quality of care. The three most-cited characteristics were: (1) dependability, (2) positive relationship and attitude, and (3) trustworthiness. Participants were also aware that the quality of the services they receive depends on the management of their care.

Dependability: Participants value when a care provider is reliable and accountable to them in terms of their care needs, and is present when the client needs them to be.

> *"Being there for me when I need them is a major concern."*

When care and services are inconsistent, participants shared that this affects the quality of care they receive.

> *"Yes, I have someone who can help me but she usually feels sick and that's become a problem."*

Relationship: Participants value when their care providers have a positive attitude and are kind to them. This kindness builds friendships between the client and care providers.

> *So, for the last three and a half years, I have been going through this in and out of the hospital, in and out of rehabs. I'm trying to live in the community, but it just seems like I can't keep caregivers. I've had caregivers come in and steal from me."*

> *"I value a person who's genuinely happy to provide the services, how they treat me, and their attitude towards me. Someone who's really there because they want to be there."*

> *"It's good just to be around people you never argue with. They're very good friends. Everybody that comes in is nice. The workers are nice. The doctors were all nice. It just makes you really enjoy it because you get peace in there."*

Trust: Another element that is critical to participants perceiving care as high quality is the trustworthiness of care providers. Trust means both that the participant trusts the caregiver to do a good job, and to be honest and not victimize them.

> *"I do not like strangers. I live alone. I feel I'm a little bit vulnerable because I live alone. I have to be very careful, because I'm in this wheelchair, about who I let in. ... I do really*

INSTITUTE FOR COMMUNITY HEALTH

Understanding the Impact and Utilization of Home and Community-Based Services among Medicare-Medicaid Enrollees from Communities of Color   13

have the trust issues thing, which is why I chose to go through the agencies to try to find a direct care worker. … I figured a direct care worker through an agency has probably some type of certification involved. Maybe they'd never had an incident brought to them or anything like that, which makes me trust letting them into my home a little more."

Many participants described low trust in service providers and shared that they may use various preventative measures to avoid situations where their trust with providers may be violated, for example by the provider stealing money, personal information, or items.

"And then what I did do, I'm going to mention this, what I did do was get some cameras in my apartment. If I'm looking for it, I come across it as missing. I'll know why. I put security cameras inside my apartment."

Importance of care management in quality: Participants also described situations such as service inconsistencies and difficulties with case managers that ultimately impacted the quality of care they received.

"Yes, some care service. I have been awarded 60 hours, and we're trying to get some more hours. But we're getting more hours and no one's working because of this company. And I've tried to ask them if they can find more than one company to try to assist me, but it seems like the person that's with me is not somewhat interested in what's going on."

Participants find their needs are not being met, fully or at all, when case managers seem unwilling to work with them to resolve issues.

Perceptions regarding the impact of race and racism on access and use of HCBS

Experiences of interpersonal racism

After discussing the various factors that influenced participants' decision making and experience with HCBS services, we asked participants about how much they felt they had been treated differently due to their race or ethnicity. This question received a mixed response. Although some participants denied ever being treated differently, many others described specific experiences of interpersonal racism from health care providers and HCBS providers.

Some participants described racist behavior from health care providers.

"I met several healthcare providers that were not as friendly as I hoped. I think that I've had issues with my ethnicity and my color from some healthcare providers."

INSTITUTE FOR
COMMUNITY
HEALTH

Understanding the Impact and Utilization of Home and
Community-Based Services among Medicare-Medicaid
Enrollees from Communities of Color

14

Other participants described racist interactions with HCBS care providers:

"It was disgusting, I guess, because for me, I had no problem with her so I really wondered why she had a problem with me."

Another participant recounted the type of conversation a paid caregiver would initiate:

"'*Every time I come in here, I'm smelling something fried. You fry cornbread too?*' and '*Oh, so the next time I stop by, you want me to bring you some Kool-Aid?*'"

Participants also stated they had been denied services due to stereotypes associated with their race and had experiences in which care providers may not hear them out and make decisions based on stereotypes.

"I think that's one of the issues why I've been denied services. I strongly believe that. I know it for a fact. It's not just personal opinion. It is so true. It's a stigma because of the color of my skin and the box that I check on applications and everything else that we are lazy, I just want to get something. I'm trying to get over."

These participants said there is a constant need for people of color to fight for and defend their perspectives in these types of interactions.

Intersectional identities: In addition to race and ethnicity, participants also described experiencing discrimination in service quality due to other elements of their identities, including disability, age, sexual orientation and religion.

"Because we're older, we're supposed to be dumber, weaker, not aware, slow. But we're alert, and I don't think these young people get that."

TAKEAWAYS: RACE AND RACISM IN HCBS

- **Many participants reported never being treated differently due to their race, while many others described both subtle and overt experiences of racist interactions with HCBS caregivers and care managers**

- **Intersectional identities also impacted peoples' experiences, especially disability and age**

- **Participants were very aware of structural and historical racism and how it negatively impacts them**

- **Participants felt that some disparities may be due to providers being less willing to serve people of color**

- **Some participants said disparities may be due to information disparities and cultural values of privacy among Black people**

- **Some participants said people of color may be hesitant to seek services due to past negative experiences of racism**

INSTITUTE FOR COMMUNITY HEALTH

Understanding the Impact and Utilization of Home and Community-Based Services among Medicare-Medicaid Enrollees from Communities of Color | 15

Structural racism

While participants discussed disparities and racism at an individual level, we also noticed that many participants saw the ways in which structural racism impacted communities of color. Some participants were well aware that, until the late 1960s, care facilities did not accept Black patients, and that some health care providers still continue to discriminate against patients of color.

> "I *can say there are some health centers that they have a review about racism. They don't really take good care of their patients and older people.*"

Participants also commented that there is an overrepresentation of White people on the welfare system which leaves people of color continuing to believe that the American government does not care enough about them.

> "*It is a very quiet kept secret that everything is not for us and will not be accessible to us.*"

Participants expressed that people of color are disadvantaged due to their neighborhoods. For example, one participant described how transportation options are worse in neighborhoods of color. Another example was the more limited availability of community resources such as fitness centers:

> "*I don't feel as if I've been treated differently but I do feel as if the things that are offered to us, it would be better if it was a different race. I would be able to go to a gym. I would be able to have a community place within my community, that's really good. That offers really good things. Even the ones that are in black communities that I've been to, I've only seen one that's really [good quality].*"

HCBS disparities

Participants were asked to discuss the finding from the literature that people of color receive HCBS services at lower rates than White people. We asked participants to share their thoughts and observations about why this may be.

Disparities due to care providers' racism: Participants mentioned that service providers have a notion that clients who are White can and will pay better than a client who is Black.

> "*I think there are some people actually that think if you are a White person, the White person will pay you better than a Black person*"

Finally, some participants perceived that some providers choose to not serve people of color due to their own discomfort, prejudice, fear, or stereotypes.

INSTITUTE FOR
COMMUNITY
HEALTH

Understanding the Impact and Utilization of Home and
Community-Based Services among Medicare-Medicaid
Enrollees from Communities of Color

16

"Me myself, I have had experience in that because like I said, I do consumer-directed home community-based services. In interviewing one of the candidates who happened to be White, she expressed that she was uncomfortable in working for a Black person."

Information disparities: Some participants felt that disparities in HCBS usage may be related to the fact that people of color may not have the knowledge and information they need regarding where and how providers and services can be accessed to address their needs. They may not have the tools and supports needed to advocate for themselves and for their family members and friends.

"Some people don't have enough information of where to get the care. People of color might not know where to see this information."

"I believe it's a lot of African-American and Muslim people that are not receiving [HCBS] due to the fact that either they don't know how to go about it. They applied but they've been turned down. So, they don't know how or what to do to go back and fight for it. They don't know how to be their own advocate. They may have family members that don't know how to advocate with them or for them. So, they just take no and fall by the wayside when they really need them."

Past experiences of racism: Some participants said that even when there may be many service options to choose from, people of color may be hesitant to seek or access services due to past negative experiences, some related to individual experiences with racism. These past experiences often leave people fearful that they might encounter similar experiences again, leading to a lack of trust in service providers and the healthcare system at large.

"I think there are so many choices that patients can pick from, but maybe the people that they see fit to provide these services for them, maybe to them, they're not available. Especially for someone that has faced things to do with discrimination, not only in terms of color but even disabilities, or just differences in sexuality and everything. I think they may be reluctant for a while to actually try to access any services that are being provided to them, maybe because they don't trust the service providers, and they don't know how to be treated. They really don't want to pass through what they have been through before."

INSTITUTE FOR COMMUNITY HEALTH

Understanding the Impact and Utilization of Home and Community-Based Services among Medicare-Medicaid Enrollees from Communities of Color   17

Cultural differences causing disparities

The focus group discussions also explored other factors that may contribute to disparities in use of HCBS among people of color. Some participants stated that Black people are private about their personal information, making them less willing to apply for programs and services, even when they need them.

"I've heard that many times that many don't apply. They just don't want people all in their business like that. They don't like it. They're uncomfortable. It's such a violation."

Another factor was the overwhelming paperwork. Participants expressed that enrolling for HCBS usually entails filling out too much paperwork, requesting that too many personal details are disclosed.

"Then sometimes people are a little private. Black folks may be a little bit more private. A bit more covered about their personal information. It's such a violation to have somebody just dig in, and dig in, and just turn your pockets inside out. Just all in your drawers. Just all in your business. That's not a comfortable feeling. They ask you 1,000 questions and it's not comfortable. It feels very violating."

Discussion and recommendations

The Focus Group conversations demonstrate that navigating and managing HCBS services is not a merely passive role of "receiving" services. Although concerns varied according to disability type and other circumstances, participants in our groups expressed feeling highly vulnerable in the context of their dependence on this care. People described the many ways they proactively managed these care relationships.

The Focus Group discussions demonstrated that people with HCBS care needs are already feeling vulnerable and overwhelmed as they attempt to find ways to meet these care needs. This sense of vulnerability is heightened for Black people and other people of color, most of whom have experienced interpersonal racism themselves, have a keen sense of the structural racism impacting their experiences, and have an understanding of the history of racism that continues to shape U.S. society today. Taking the leap of faith to trust non-family members with their care is therefore harder for members of these communities. The literature supports this

INSTITUTE FOR COMMUNITY HEALTH

Understanding the Impact and Utilization of Home and Community-Based Services among Medicare-Medicaid Enrollees from Communities of Color   18

finding, suggesting that finding willing and able providers to serve people of color is more challenging.

Under these circumstances, trust within caregiving relationships is critical. Relationships between caregiver and care recipient work best when they are not merely transactional but are characterized by trust, reliability, and caring.

A number of recommendations for reducing the HCBS disparity arise from this work.

I.   **Trauma-informed, culturally competent outreach**: We have seen that mistrust among communities of color is a barrier to putting needed services in place. In order to reduce HCBS disparities, therefore, we recommend the development of a system for outreach that is trauma-informed and culturally competent. Suggestions from focus group participants include making testimonials and recommendations available, credentialing for prospective caregivers, and having a centralized, cross-agency directory where patients could look up caregiver credentials and experience.

II.   **Valuing both family and paid care**: The reality of many of our participants is that they combine paid care with family care in creative and pragmatic ways; family fills gaps in care, and family coordinates and oversees paid care. In circumstances when family members are able to get paid for their services, this enables them to be able to afford more time to devote to caregiving. Acknowledging the labor of family members, including the oversight and gap coverage roles, could lead to a better understanding of the full degree of work required to coordinate care. Family caregiver respite support would benefit everyone involved by reducing burnout and financial strain. Under-valuing paid caregiving also impacts patients, as well. Low wages lead to high turnover rates, lack of engagement of employees, and strain on relationships with patients. Therefore, the following actions would be helpful:

- Increasing compensation to paid caregivers;
- In circumstances where not already available, wages for family caregivers, including for coordination and oversight roles should be explored, and;
- Respite programs for family caregivers should be strengthened and expanded.

III.   **Trust-building mechanisms**: As we have shown, trust in caregiving relationships is fundamental to reducing the HCBS disparity. Both of our previous recommendations address trust. We also recommend specific mechanisms to increase trust including:

- Adding additional mechanisms for the oversight and quality control of services; this should include community-led mechanisms, such as beneficiary advisory committees
- In addition to increased wages, other steps to decrease turnover of paid caregivers, such as career ladders and increased benefits, and;

INSTITUTE FOR COMMUNITY HEALTH

Understanding the Impact and Utilization of Home and Community-Based Services among Medicare-Medicaid Enrollees from Communities of Color

19

- Explicitly encouraging relationship-building between caregiver and patient by budgeting extra time for this, naming it as a priority, and following up on it during supervision of caregivers.

IV. **HCBS users understood as managers and bosses**: Many of our participants already use strong management skills as they actively coordinate their own caregiving needs with family members and/or paid caregivers. Redefining the role of care recipient from one as passive and dependent to one of actively managing could both add dignity and reduce feelings of vulnerability for patients. It is important that this should not be merely a rhetorical shift; we recommend offering management tools and training to those in need of caregiving services or their coordinating family members. We also recommend implementing mechanisms by which paid caregivers could be held accountable to care recipients.

INSTITUTE FOR
COMMUNITY
HEALTH

Understanding the Impact and Utilization of Home and
Community-Based Services among Medicare-Medicaid
Enrollees from Communities of Color

20